

## The Path Towards a Great Future in Education: Self Advocacy



By Stephen Hinkle  
Self Advocate

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## My Background



- Have Autism (Asperger Syndrome)
- Grew up in the Special Ed System
- Was in Segregated Classes till 4th Grade
- Inclusion from 5<sup>th</sup> grade till college
- Graduated College – BA in Computer Science from San Diego State University
- Obtained my masters from Northern Arizona University – going for a masters in Disability Policy Studies
- National Speaker for 13 years and have presented in 17 states

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## What is “Special” about “Special Education”?



- “Special Education” is a term that refers to people with special needs getting educated.
- Special Education sometimes allows people to receive additional supports or services that others may not receive due to their special needs.
- Some Common Supports:
  - Test Accommodations
  - Curriculum Changes
  - Additional Therapies such as speech, OT, PT, social etc
  - Use of “assistive technologies”
  - Communication in a different way if a person cannot speak or write
  - Adaptive PE
  - Transportation Supports
  - Extended School Year



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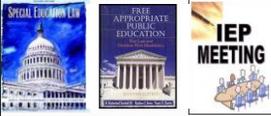
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## What is a Special Education Student Entitled to?



- A Free and Appropriate Public Education
- Access to the General Education Curriculum
- Early Childhood Supports
- Individualized Education Program (IEP)
- Appropriate Supports and Services
- Be Taught in the "Least Restrictive Environment"
- Supports for transition to adulthood until one graduates high school or reaches age 21 (whichever comes first)



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## What is Inclusion?



- Being in the regular classroom like all the other kids (as opposed to a segregated class)
- IEP Goals and supports accommodated in the regular classroom
- Supports and Services (tests, OT, PT, Speech, Social Skills, curriculum modifications, assistive technology, with little or no pull out)
- Have access to school related extracurricular activities

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## Promoting Inclusive Disability Culture in School: What People Can Do to change the outcomes



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## Historic Treatment of People with Special Needs



- Years ago, locking people with disabilities in institutions their entire life was very common
- Many were sent to segregated schools where they were given inferior treatment
- Treated as "barbaric"
- Even today, there are many students with special needs in segregated classes

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## Some Sad Statistics I must Share



- The unemployment rate for people with disabilities is over 73% according to the organization TASH in 2009.
- More than half of people with disabilities do not have High School Diplomas that actually count for anything, like college admission or job placement.
- Many people with disabilities live at a poverty level or lower.

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## Beginning to Advocate for Yourself



### • Get to know yourself:

- What are your Strengths?
- What are your Interests?
- What are your Hobbies?
- What are your Personal Needs?
- What are your Academic Needs?
- What are your Social Needs?
- What are your Support Needs?
- Where do you fit into the community?
- What else is important to you?
- Where do you want to be in the next 5 or 10 years?
- Which things could I do better or improve on?
- What bothers me and what could I change?
- Am I enjoying a quality life?

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## Self Evaluation of your Academic Environment



- Do you believe you are **achieving and learning the content**?
- Are you **achieving your IEP goals**?
- Are you making **adequate academic progress**?
- Are you **comfortable or uncomfortable** while in school?
- What are you **good at** and what could you use some improvement on?




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## Self Evaluation of your social needs in School



- Are you making adequate **social progress**:
- Are you **making friends** easily?
- Are you able to maintain **social relationships**?
- Do you understand the **skills** to do the various **social activities** such as:
  - School Spirit Activities
  - Recess / PE
  - Lunchtime Fun
  - Assemblies
  - Plays
  - Concerts
  - Sports
  - After School Programs
  - VAPA Programs
  - Dances
  - Etc
- Are there any **social skills** from the **recreation and/or etiquette** realms that you could use improvement on?

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## Self Evaluating Your Support Team



- Do you think they are **doing their job well**?
- Are you in your **comfort zone** when working with them most of the time?
- Is there anything that **bothers you about their services and the way they are delivered**?
- Do you find that the **services they are delivering are beneficial to your learning** and why or why not?
- **Support teams can include:**



- Teachers
- Parents
- Therapists (e.g. OT, PT, Speech, Adaptive PE, etc)
- School Admin Staff
- Outside Agencies
- Friends
- Others

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## Giving Feedback to your support team



- What **feedback** do you want to give the team supporting you on what they are doing well for you?
- What do your **friends think of your progress** in school or have to say about you?
- What else could your **support team do better?**
- Is there any policies or supports that are **hindering** your progress and/or causing **learned helplessness** for you?

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## Transition Planning



- Transition is a plan for a person with special needs to begin their life after they **exit high school**. These can include things such as:
  - College
  - Independent Living Skills
  - Job Skills
  - Job Training
  - Adult Social Life Activities
  - Bus Access
  - Driver Education
  - Raising a Family
  - And Much More!
- **At age 16**, life after high school transition planning **must begin**. (It can begin earlier if a member of the IEP team requests)

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## Transition Planning



- This can involve other agencies such as **Dept of Economic Security**, colleges, **Social Security** and others
- There are **many tracks** you can choose to take depending on your needs:
  - Graduate with your HS class at age 18 (typically the **academic track**)
  - Take **extra years of High school** if you need them up to age 21 (usually for **functional skills and/or academics at a slower pace**)
  - Do your age 18-21 years in **another setting** such as a **university**, and/or **work training setting** (e.g. not on the HS campus).
- Depending on the **path(s)** you choose, it will affect your potential funding sources, service availability, career path potential, and more .

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## Disabled or "Differently Abled"?



- When referring to someone with special needs, **call them by name** and treat them with **respect**.
- **Never** call anyone "retarded" or make jokes about ones disability
- Recognize ones **strengths**, not ones deficits first. This treats one as welcoming
- Use "**Person First language**" rather than disability first language

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## Alternative Communication Etiquette



- When someone uses an **alternative communication system**, learn how to understand it and even sometimes respond back using it.
- Sometimes people with special needs will take **longer to respond** and the **answers given may be simpler**.
- When interacting or doing certain activities, one may have to **adapt what they are doing** to accommodate a person who may have movement differences or a different brain functioning level.

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## More Disability Etiquette



- Seeing eye dogs and monkey helpers should **never be petted or touched** without permission
- When one uses a wheelchair, **do not push it** unless the person asks you to. Opening doors for those in wheelchairs is a kind thing to do for them though.
- Aides and Paraprofessionals are an exception to the "**Don't go near the kid when an adult is there rule!**"

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### Evaluate the Culture of Disability in Your School

WILL I BE ABLE TO GET TO ALL THE PLACES IN MY SCHOOL THAT MY NON-DISABLED FRIENDS LOVE?

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### Evaluate the Culture of Disability in School

Or

- Are people with special needs **included or segregated** in academic classes in your school?
- Where are "special education rooms" located in your school?
- Are supports delivered in the **regular classrooms** or in separate rooms?
- Are people with special needs included in **extracurricular** and **school spirit activities**?

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### Cultural Evaluation Continued

- Are students with special needs able to **achieve their potential** and excel in the school?
- How much **access** do kids with special needs have access to the **general education curriculum**?

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## Disability Etiquette in School



- How is your schools general knowledge of **disability etiquette** among the students and how well is it **practiced by students and staff** in the classrooms, hallways, cafeterias, etc?
- Are the **students who have special needs** well respected citizens in your school?

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## Support Workers, Friendship, and Isolationism



- Students need to know that is OK to **go near someone with an aide or paraprofessional near them.**
- Kids that don't **know this exception** often leads to people with aides **not having any friends!**
- It is very important to recognize **"inclusion"** from **"an island in the mainstream"**

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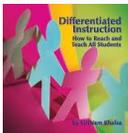
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## Academic Curriculum and the Disability Culture



- Some people who receive special education services may need **assignments and/or tests modified** to meet their needs, such as:
  - Easier questions
  - Less numbers of questions
  - Tests showing picture based questions
  - Alternative questions that align with a child's IEP goals
- Note: in many cases it is possible to accomplish this with **little or no change to the subject** that is being taught that day!
- Is **modified instruction** being provided in your school to **the kids that need it** and are other kids accepting and treating the kids that receive it as welcomed members of their class?

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## Are Kids With Disabilities Involved In All Areas of the Curriculum?



- Core Subjects:
  - English
  - Language Arts
  - Math
  - Science
  - History
  - Social Studies
- Electives:
  - PE
  - VAPA
  - Home Economics
  - Industrial Arts
  - Career Tech Ed
  - Computers
  - And Many Others

- It is important that every child with special needs gets a **well rounded education that interests them.**
- To accomplish this, people with special needs need to be included in **as many subjects as possible.**
- The **"core"** subjects are usually the most critical when it comes to IEPs and standards but **all are important.**
- It is important that those with special needs have access to the **subjects in school they love so they have "fun" in school.**
- Lastly, it is best for supports and **services to be delivered in the classroom** as opposed to "pull out".

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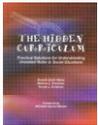
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## Extracurricular Activities and Disability Culture



- Is **direct instruction** in extracurricular and school spirit activities **being taught** to those that need it in your school?

Some people with special needs **may not learn the social activities** without being directly taught the **skills for how to do them.**

Common skills for extracurricular activities which some kids **may need to be taught** could include:

- Game Play Rules
- How to dance
- How to be a friend
- Protocols for interacting with others
- Audience Interaction Skills
- Manners and Etiquette
- Conversation Skills
- Meanings of Slang
- Banter
- etc

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## Adapting in the Extracurricular Realm



- Sometimes sports and recreational games may need to be adapted for people with special needs or movement differences
- Universal design makes all the activities accessible.

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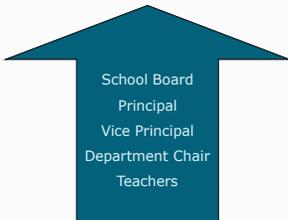
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## The Chain of Command



- There is a hierarchy in most schools in how the staff are organized and whom reports to whom
- When there is an issue with a policy that is not being resolved, sometimes it is best to go to the person higher up.

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## Addressing Disability Policy Issues In Your School



- Self Advocates have the **power to make big change!**
- Discuss ways in which the **policy could be changed** for the better!
- Present the issue in a **positive manner**
- Determine **which teams or groups of people** it would be best to approach with the proposed changes.

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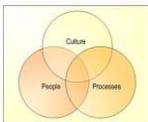
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## Change Happens Slowly



- Arrange an **appropriate meeting time** with the team
- **Don't expect changes overnight**, as sometimes you will run into resistance, budget concerns, legal issues, or other roadblocks.
- Change often **happens a little at a time**.




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## Don't be afraid to speak out!



- Sometimes **school discipline policies** make students **afraid of speaking out** for fear of discipline.
- If meeting times are **arranged** and you market the **change as positive**, you should not be disciplined.
- You should speak out to staff if the relationship between you and your support staff is not **productive and comfortable** for you
- Disability policy issues should be spoken to staff at **appropriate times**.

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## Addressing Various Teams



- **Inclusion / Segregation:**
  - Teachers
  - Principal
  - School Board
- **Accessibility of Rooms**
  - Physical Plant / Maintenance
- **Instructional / Curriculum:**
  - General Ed Teachers
  - Special Ed Teachers
  - Inclusion Facilitators
- **Culture / Disability Etiquette:**
  - Teachers
  - Peers
  - Support Staff
  - Principal

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## Addressing Various Teams, Continued



- **Student Supports / Comfort:**
  - Teachers
  - Aides / Paraprofessionals
  - Support Staff
- **Extracurricular:**
  - Teachers
  - VAPA Departments
  - PE Dept
  - ASB / Student Government
  - Extracurricular Staff
  - Peers
- **Assistive Technology:**
  - Teachers
  - Support Staff
  - Tech Support
- **Room Locations of Resource Rooms:**
  - Principal
  - Teachers

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## Leading your own IEP Meeting



- **Choose your own team** (at minimum you must have at least one of each of the following at the meeting):
  - General Ed Teacher
  - Special Ed Teacher
  - Parent
  - Administrator / PEA Rep
  - Individual to interpret Results

You can invite others to your IEP meeting such as **peers, advocates, specialists,** and others!

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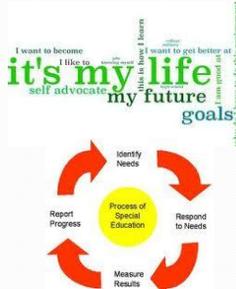
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## Leading your own IEP Meeting



- **Set goals for yourself**
- **Share your thoughts** for the next year of school in terms of **academic and social issues**
- Understand the **issues** your teachers and parents have to say about you
- Make **recommendations for your future** to your teachers and support staff

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## Student Led IEPs: Academics



- Help select the **curriculum** in terms of **core subjects and electives** you will receive
- Advocate for any **modifications** you will need to the **curriculum**
- Share with the IEP team your needs for **assistive technology**

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### Student Led IEPs: Extracurricular



- Share your **extracurricular needs** with the team and **set some extracurricular goals**.
- Tell the team which **activities you would like to participate in**.
- Explain to your team if you are **having trouble learning how to do an extracurricular activity** or want to learn more about a specific activity.

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### Student Led IEPs: Test Results



- Test results can reveal things you might be **good at** and other things you may **need to work on** later.
- Test results should be **taken with a grain of salt** and put into **context** with other known information about the student such as **his/her strengths, interests, and goals**.
- **Don't be offended by poor scores** or low age equivalency ratings on one or more tests. These again have to be **put into context** with other information about the student.
- All Tests can have **bias** in their results.

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### Student Led IEPs: Know your Legal Rights



- Various **laws exist** to protect the rights of people with special needs in access to **education, supports, and services**
- If you are denied a service or **feel your rights have been violated**, you have the right to get a second opinion through the legal system via **mediation, arbitration, due process, and/or trial**.
- If you need to bring a legal case or mediation, **first research your rights and then call an attorney**.

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### Many With Special Needs Go on to Meaningful Lives After High School



- Community College
- 4-Year University
- Vocational / Technical College
- Graduate School
- Internships
- Employment
- Military Service
- Live on your Own
- Live with Roommates
- Live in College Housing (Dorms, Apts. etc)
- Relationships
- Marriage
- Adult Life Activities
- And many more!

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### What society can do to improve the outcomes of persons with disabilities



- Work to make services **focus on improving ones strengths**, not be based on ones deficits
- Work to end the “**culture of poverty**” among people with disabilities by creating services and allowing **collaboration between agencies** so that persons with disabilities can pursue **real career paths that pay a living wage and have a future.**

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### There is more society can do, too!



- Encourage your school staff to **update outdated support procedures** that lead poor outcomes and replace them with ones that lead to the best outcomes.
- Don't assume a person will be receiving supports for life, it is **possible that they will “outgrow” their supports** or need new ones as a person **becomes more independent.**

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## What Society can do as a whole to improve outcomes for persons with disabilities



- Advocate for **full compliance with all disability rights laws.**
- Give every child the opportunity to make and **complete the path from Preschool to Grad School.**
- Promote **Inclusion**
- Work to **raise the graduation rates** of high school and college students with disabilities
- Work to create a generation in which **parents do not have to bend over backwards** to get what they need for their child with a disability as it is very challenging for many parents in the current system.

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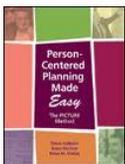
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## Persons with Disabilities can chose their path in Life



- Break down "**Low Expectations Barriers**"
- End the **culture of poverty and unemployment** among people with disabilities
- Allow persons with disabilities to **choose their path in life**

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## What Society as a whole can do



- Provide support in assisting persons with disabilities who need to learn **social skills, manners, etiquette, and how to be friends.**
- Restore civility and **educate the public on disability etiquette** and treat persons with disabilities as **valued members of their community**
- When you meet someone with a disability, **be their true friend**
- Create a culture in which people with **special needs are welcomed.**

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## The most important of all



- BE THEIR ADVOCATE!!!!
- BE THEIR TRUE FRIEND!!!
- HELP OTHERS WITH SPECIAL NEEDS MAKE THE DECISIONS THAT WILL LEAD THEM TO A GOOD FUTURE AHEAD USING ALL THEIR TALENTS AND STRENGTHS!!!!!!

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